Chronic disease and illness care

Adding principles of family medicine to address ongoing health system redesign

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he personal and economic burden of chronic disease and illness is a serious challenge for Canadians.1 Public policy has a strong focus on chronic disease, emphasizing health system redesign with the introduction of a series of different health system models to enhance population-based prevention and chronic disease management.^{2,3} As a key provider of chronic care, family medicine is being exhorted to take up these challenges. Is family medicine being pushed and pulled between the burden of chronic disease and health system redesigns? Or is family medicine facing unbridled opportunities to actualize its core principles?

Nature of conditions

While the terms chronic disease and chronic illness are often used interchangeably in the clinical literature and in health services policy and organization, they convey different meanings that require clarification (Table 14-6). Chronic disease is defined on the basis of the biomedical disease classification, and includes diabetes, asthma, and depression.4 Chronic illness is the personal experience of living with the affliction that often accompanies chronic disease. It is often not recognized in health systems, because it does not fit into a biomedical or administrative classification.⁶ Family



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medicine principles champion the patient-centred care of chronic illness.5

Chronic disease and illness occur in complex interdependencies and continue across the lifespan. They are greatly influenced by socioeconomic status, education, employment, and environment.2 Thus, unless the underlying determinants of health, well-being, and the community context are addressed through a continuum of health promotion and empowerment from wellness to disease and illness care, the least advantaged will experience widening disparities in outcomes.²

Chronic care model

The chronic care model (CCM) describes chronic care as "the prevention and diagnosis, management, and palliation of chronic disease" and is internationally accepted as the main strategic response to the challenges of chronic disease.7 The model calls for the redesign of health care to provide continuous, coordinated multi-faceted systems of health service delivery.3 The CCM is based on a Cochrane systematic review of chronic care interventions.7 For example, key elements of the CCM, as identified in the research literature,8 include the following:

- personnel and care processes to support proactive care, including planned care and care coordination, and scheduling or coordination of visits and follow-up;
- · decision support for providers, including disease management guidelines and protocols;

Table 1. Descriptions of chronic disease and chronic illness

TERM	DEFINITION				
Chronic disease	Chronic disease has various definitions: "long in duration—often with a long latency period and protracted clinical course; of multi-factorial aetiology; with no definite cure; gradual changes over time, asynchronous evolution and heterogeneity in population susceptibility." ⁴				
	Diseases referred to as <i>chronic</i> include both non-communicable diseases, such as diabetes, heart disease, chronic obstructive pulmonary disease, cancer, and depression, and communicable diseases, such as AIDS.				
	Chronic disease refers to a diagnosis categorized in the biomedical system according to etiology, pathophysiology, signs, symptoms, and treatment that also implies an expected long duration and lack of cure. ⁴ Conditions, syndromes, and disorders are similar, but are less well-defined. ⁴				
Chronic illness	Chronic illness refers to the lived experience of long-term bodily or health disturbance, ⁵ whether related to a communicable or non-communicable disease, condition, syndrome, or disorder; and how people live and cope with the disruption. It is "experience of intrusive bodily or mental unwelcome unpleasant sensations" and includes phenomena such as fatigue, weakness, anomie, confusion, or social stigma. ⁶				

- · information systems to ensure access to timely and relevant information:
- support for patient empowerment and self-management;
- community resources to inform and support patients;
- · system support for chronic illness care among providers integrated into care networks.

A synthesis of randomized controlled trials and controlled before-after studies of various components supports the CCM, although there have been no published trials evaluating the full effect of the comprehensive model, and there have been mixed results related to how to implement adapted components.9 Nonetheless, this CCM is being adapted and adopted by most provinces in Canada. Earlier adopters have been British Columbia and Alberta, spreading from west to east from Group Health Seattle and the Wagner group. Local adaptation and adoption of the CCM are endorsed by the World Health Organization. These models promote proactive patients, communities, and providers; integrated and coordinated care, which includes office systems that support adherence to disease management guidelines and the promotion of structured and planned care; teamwork; care coordination; and selfmanagement support (**Table 2**⁷).

Variations of care strategies

Currently, as local variations of the CCM are being implemented, there are intense activities afoot to integrate family medicine—a medical discipline—into comprehensive primary care (PC) and primary health care (PHC) models.

A medical care model is the term for the set of procedures in which all doctors are trained in Western medicine. This set includes complaint, history, examination, ancillary tests if needed, diagnosis, treatment, and prognosis with and without treatment, based on a biomedical classification system.4

Primary health care incorporates personal care with health promotion, the prevention of illness, and

Table 2. Chronic care model: Essential elements of a health care system that encourage high-quality chronic disease care. The 2 elements implied but "missing" from the 4 principles of family medicine are the centrality of the patient journey, including self-management (blue shading), and the role of family medicine in multiple health systems models (green shading).

Self-management support

Empower and prepare patients to manage their health care. Patients are encouraged to set goals, identify barriers and challenges, and monitor their own conditions. A variety of tools and resources provide visual reminders. Emphasize to patients their role in managing their health. Use effective self-management support strategies that include assessment, goal setting, action planning, problem solving, and follow-up. Organize internal and community resources to provide ongoing self-management support to patients (eg, patient interest groups).

Community involvement

Mobilize community resources to meet needs of patients: community resources, from school to government, non-profit to self-help organizations. Bolster health systems' efforts to keep chronically ill patients supported, involved, and active.

Create an organization that provides safe, high-quality care. A health system's business plan reflects its commitment to apply the chronic care model across the organization. Clinician leaders are visible, dedicated members of the team. Visibly support improvement at all levels of the organization, beginning with the senior leader. Encourage open and systematic handling of errors and quality problems.

Delivery system design

Assure effective, efficient care and self-management support. Regular and proactive planned visits that incorporate patient goals help individuals maintain optimal health and allow health systems to better manage their resources. Visits often employ the skills of several team members. Define roles and distribute tasks among team members of planned interactions to support evidence-based care. Provide clinical case-management services for complex patients with regular follow-up by the care team. Give care that patients understand and that agrees with their cultural backgrounds.

Decision support

Promote care consistent with scientific data and patient preferences. Clinicians have convenient access to latest evidence-based guidelines for care of chronic conditions. Continual educational outreach reinforces utilization of standards. Embed evidence-based guidelines into daily clinical practice. Share evidence-based guidelines and information with patients to encourage their participation. Integrate consultant expertise and primary care.

Clinical information systems

Organize data to facilitate efficient and effective care. An inclusive list (registry) of patients with a given chronic disease provides the information necessary to monitor patient health status and reduce complications with timely reminders for providers and patients. Identify relevant subpopulations for proactive care. Facilitate individual patient-care planning. Share information with patients and providers to coordinate care. Monitor performance of practice team and care system. For more information on the chronic care model, go to http://www.improvingchroniccare.org/.

Adapted from Wagner et al.7

community development. The philosophy of PHC includes the interconnecting principles of equity, access, empowerment, community self-determination, and intersectoral collaboration. It encompasses an understanding of the social, economic, cultural, and political determinants of health.10

Primary care is more clinically focused and can be considered a subcomponent of the broader PHC system.11 Until recently, PC was considered health care provided by a medical professional that is a client's first point of entry into the health system. Primary care in Canada is increasingly multidisciplinary, with nurses and allied health and other community providers working in teams with family physicians.

The new orientations for PHC set out in the 2005 Declaration of Montevideo,12 to which Canada is a signatory, are predominantly a response to the challenge of burgeoning communicable and non-communicable chronic disease with health services that remain attuned to acute care paradigms. 13 Table 3 illustrates the evolving health system models in which family medicine is or will be operating to provide future chronic disease and illness care in Canada, starting from the basis of the biomedical disease model of a medical speciality.14

Principles of family medicine

Family medicine integrates disease and illness. Family physicians commit to "integrate a sensitive, skillful, and

appropriate search for disease. They demonstrate an understanding of patients' experience of illness (particularly their ideas, feelings, and expectations) and of the impact of illness on patients' lives."5

A key element of the family physician role is "healing" the patient, as well as managing the disease.5 This is not achieved by solely addressing the biological components of the disease. Increased opportunities for chronic disease management, self-management, and prevention might be limited by a focus on disease. Furthermore, the CCM or chronic disease management programs can focus on a particular phase of the chronic care trajectory to the exclusion of person and illness care, especially when the disease model breaks down, such as in the phase of preterminal care.3 Consequently, family physicians will increasingly need to take a lead with respect to the care of individuals, in their families and in their communities. This will need to encompass the heterogeneous asynchronous evolution of chronic disease and illness across the lifespan through asymptomatic to acute, chronic, and palliative care.

Family medicine is a community-based discipline. Improving chronic care in the health system, in communities, in organizations, in clinical practice, and with patients¹⁵ involves the following: patient- rather than disease-centred care; continuity of management, relationships, and information; integration of sectors, disciplines,

Table 3. Evolving health system models in which family medicine operates: None of the models or systems are discrete and all are constantly changing and adapting and adopting each others' ideas. The 2 elements implied but "missing" from the 4 principles of family medicine are the centrality of the patient journey, including self-management (blue text), and the role of family medicine in multiple health system models (green text).

HEALTH SYSTEM MODEL CHARACTERISTIC	CHRONIC CARE MODEL	FAMILY MEDICINE AS MEDICAL SPECIALTY	MULTIDISCIPLINARY PRIMARY CARE	NEW ORIENTATIONS OF PRIMARY HEALTH CARE
View of health	Absence; control of disease; quality of life	Absence; control of disease	Absence; control of disease; quality of life	Positive well-being
Locus of control	Health system managers, self-management	Medical practitioners	Health professionals	Communities, families, and individuals
Main focus	Health systems Patient self-management Providers	Individuals Cradle-to-grave disease prevention and control through medical interventions	Practice-based Cradle-to-grave disease prevention, management, and care through provider interventions	Population- and community-based Improve individual's family and community, healthy living, and equity
Health care providers	Multidisciplinary systems, including physicians, intersectoral and community collaboration	Family physicians with other health care providers	Family physicians as part of multidisciplinary teams	Multidisciplinary networks include FPs and intersectoral collaboration
Strategies for health	Disease prevention and management systems across health sectors Self-management, care coordination, evidence, and community involvement	Medical interventions and systems Acute care paradigm between secondary and tertiary care; evidence-based guidelines	First-level health system Prevention, chronic disease management; structured and planned care; self-management with professional, peer, and family support	Population health systems Health promotion, prevention, self-care, and illness support; address inequalities and determinants; community empowerment; accountability

and medical, preventive, and population-based care; and the need for appropriate funding models and incentives. This involves opportunities for communityactivation and decision-making partnerships among FPs, professionals, patients, caregivers, hospitals, and community members, and empowerment in health and illness for the individual, family, and community.

The family physician is a resource to a defined practice population. Family medicine recognizes that some community members and disadvantaged groups face exaggerated higher disease risks and disease rates, greater suffering with illnesses, and less ability coping with disease and illness than the general population because of poverty, social exclusion, and other disadvantages.² Family physicians use referral to specialists and community resources judiciously; resource management maximizes health system efficiency and can require opportunities in a community network of providers for resource effectiveness.

Patient-physician relationship is central to the family physician role. As an unintended consequence of system change, illness and healing through a long-term personal patient-physician relationship can increasingly be overlooked in disease and population-focused care.12 However, putting the individual, the family, and the community at the centre of the system with chronic disease and illness care should reshape care, allowing

greater emphasis on self-care, and the recognition and support of illness in its community context, along with the determinants of health.

Framework for chronic care

The principles of family medicine address both chronic disease and illness, with longitudinal care that is patientcentred, relationship-based, integrated, and community oriented (Table 4). Thus, these principles are synergistic with the CCM, although it places less emphasis on the role of the FP and the doctor-patient relationship. As PC and PHC are implemented as multidisciplinary and population-based systems, respectively, the substantial system redesign aligns both with the CCM and with the family medicine principles. However, as the multiplicity of approaches has the potential to create confusion and frustration, an explicit coherent chronic care framework is needed to adapt to the way family medicine works. Such a framework is needed to model the pathways through health, disease, and illness in the life course of those afflicted, and the family medicine roles across the phases of prevention, treatment, and care. Without such a framework on which to build evidence, there are hidden threats as well as opportunities.

Comparison of the roles of the principles of family medicine in relation to the health system models in which family medicine operates—the chronic care, medical care, PC, and PHC models—described in Table 2 and Table 4, identified gaps and synergies.

Table 4. An exploratory mapping of the principles of family medicine in relation to the changing health system models: Chronic care, medical care, primary care, and primary health care models.

	MODEL				
PRINCIPLES OF FAMILY MEDICINE*	CHRONIC CARE MODEL	FAMILY MEDICINE AS MEDICAL SPECIALTY	FAMILY MEDICINE INTEGRATED WITHIN PRIMARY CARE	NEW ORIENTATIONS OF PRIMARY HEALTH CARE	
Family medicine locates the patient journey through health, disease, and illness at the centre of health systems Empowerment, with self-care, and peer and community support, is essential	++	0	?	+	
The family physician is a skilled clinician who integrates disease management and an understanding of illness	?	++	?	?	
Family medicine is a community-based discipline	?	+	++	++	
The family physician is a resource to a defined practice population	+	+	++	++	
Patient-physician relationship is central to the family physician role	?	+	++	0	
Family medicine operates in multiple health system models—leading and adapting health system redesign	++	0	+	++	

⁺⁺⁻large role, +-small role,

^{?-}possible role, 0-no current role.

^{*}The 2 elements implied but "missing" from the 4 principles of family medicine are the centrality of the patient journey, including self-management (blue shading), and the role of family medicine in multiple health system models (green shading).

In particular, illness and healing through a long-term personal patient-physician relationship can increasingly be overlooked in an overly disease-orientated or population-focused emphasis. None of the models or systems are discrete and all are constantly changing and adapting and adopting each others' ideas. The 2 elements that emerge as "missing" from the 4 principles of family medicine are the centrality of the patient journey, including an emphasis on self-management support with an activated community, and the emerging role of family medicine in multiple health system models and ongoing system change.

Additional principles

Given current policy imperatives, it is important that family medicine advocates for patient-centred care and takes a leadership role in system redesign implementation. I propose the following 2 principles to enhance the existing 4 principles of family medicine as a framework for system redesign to address the burden of burgeoning chronic disease.

Family medicine locates the patient journey through health, disease, and illness at the centre of health systems. Empowerment, with self-care and peer and community support, is essential. An individual traverses their unique disease and illness pathway through life stages and internal biological and external social environments. Being empowered by taking control of their health and disease, supported through self-management and self-care by family, peers, and professionals, guarantees the best outcomes for an individual.¹⁵ There are numerous care relationships, predictable and unpredictable positive and negative influences, and feedback loops through which the patient and FP must navigate. The long-term patient-physician relationship and organizational structure of family practice and PC ideally provides a nexus for care coordination and continuity among these trajectories, enabling health and ameliorating illness as well as disease.11 Family medicine thus must locate (and advocate for) the centrality of the patient journey in preventive, acute, chronic, and palliative care across the asynchronous evolution of disease and illness in complex personal and health care environments.11

Family medicine operates in multiple health system models—leading and adapting health system redesign. In reality it is difficult to implement the full CCM, which itself might focus on disease more than illness. This would require an integrated highly functional effective health system with appropriate frameworks for disease and illness. It would require a seamless integration of models of care, funding, and organizations, as well as sharing a common philosophy of care amongst patients, caregivers, professionals, hospitals,

and the community or compartmentalization, which has not been demonstrated to be implementable. In addition, for each individual or community, different or multiple approaches are likely to be needed at different times. Family medicine works in different models to coexist interdependently over time as disease, illness, and treatment stages evolve. Therefore, as a key player, it has an essential leadership role in shaping integrated care and system changes from a grassroots perspective.

Conclusion

Changing (whether radial or evolving) policies for transforming health systems in response to the challenges of chronic care align with Canada's principles of family medicine. The patient-physician relationship appears particularly important, yet vulnerable in system reforms, as it is the element of care that most specifically addresses illness through a long-term personal therapeutic relationship. In addition, given the complexity of models of health system reform, an expanded framework is needed in order that the potential of family medicine to manage disease, health, and illness is fulfilled. The 4 principles of family medicine represent core values that can frame the main models of system redesign to address the burden of chronic disease. I recommend 2 new principles of family medicine to complement the existing 4 principles. These principles are needed to address the increasing recognition of the centrality of the patient journey through health, disease, and illness with self-care and empowerment. Ongoing health system reforms necessitate a leadership role for family medicine as an important provider of chronic and lifelong care in an environment of almost continual health system redesign and adaptation. Such adaptive and responsive family medicine leadership should be informed by an understanding of their individual, community, and population needs, and what makes health systems effective.

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Competing interests

None declared

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